The experience among patients with multiple dental loss as a consequence of treatment for head and neck cancer: A qualitative study

Elsevier Editorial System(tm) for Journal of Dentistry

Manuscript Draft

Manuscript Number: JJOD-D-18-00796R1

Title: The experience among patients with multiple dental loss as a consequence of treatment for head and neck cancer: A qualitative study

Article Type: Full Length Article

Keywords: Dental loss, head and neck cancer, patient experience, qualitative research, shared decision-making, dentists.

Corresponding Author: Dr. Cherith Jane Semple, PhD, BSc (Hons) Nursing, RN

Corresponding Author's Institution: Ulster University / South Eastern Health & Social Care Trust

First Author: Roisin Parahoo, MSc Global Health

Order of Authors: Roisin Parahoo, MSc Global Health; Cherith Jane Semple, PhD, BSc (Hons) Nursing, RN; Simon Killough, BSc (Hons) BDS, MFDS FDS (Rest Dent), PhD; Eilis McCaughan, RGN, Dip Oncology Nursing, BSC, PGDHE, PHD,

Abstract: Objectives: To explore the experience among patients with multiple dental loss as a consequence of treatment for head and neck cancer
Methods: Semi-structured qualitative interviews were conducted with a purposive sample of fifteen people with head and neck cancer, who had multiple teeth removed as part of their tumour resection or extracted pre-radiotherapy. The interviews were digitally recorded and transcribed for analysis by two researchers, independently.
Results: The interview data were categorized into four themes: 1. Pre-treatment experience of being informed that teeth had to be removed, 2. Impact of dental loss post-treatment, 3. Coping with dental loss, and 4. Getting dentures and implants. Patients receiving primary radiotherapy felt the time between being informed of requirement for dental extractions and actual extractions was short. Dental loss was detrimental to all patients in terms of eating, speaking, socially and their intimate lives.
Conclusions: Patients whose primary treatment was surgery, appeared more accepting of dental loss. Whereas, those having primary radiotherapy, there seemed to be a focus on prevention of radiotherapy-induced complications, with limited choices and recognition on post-treatment dental functionality. This study showed the negative impact of dental loss on patients' quality of life.
Clinical significance: Dentists should be aware of the post-treatment implications of dental loss on patients' lives; presenting this, as well as the clinical advantages for extractions, to aid decision-making. Patients should be informed of the lack of conclusive research evidence regarding pre-radiotherapy dental extraction. There should also be clear pathways regarding post-treatment dental-related rehabilitation.

Dear Mr Christopher D. Lynch,

TITLE of manuscript - The experience among patients with multiple dental loss as a consequence of treatment for head and neck cancer: A qualitative study

As Editor-in-Chief, we kindly request that the above manuscript is considered for publication in Journal of Dentistry. As recorded in the "Permission note" this manuscript has not been submitted for consideration of publication in another journal. Furthermore, we wish to confirm that the submitted work, including tables, are original. All authors have been instrumental in the research conducted and have read the final version of the paper which has been submitted.

We look forward to hearing from your editorial team in the near future.

Kind regards,

Dr Cheirth J Semple, Reader in Clinical Care Nursing, Ulster University / SEHSCT, Belfast

(corresponding author)

Dear Mr Christopher D. Lynch,

TITLE of manuscript - The experience among patients with multiple dental loss as a consequence of treatment for head and neck cancer: A qualitative study

As Editor-in-Chief, Dear Prof. Lynch,

On behalf of our research team, many thanks for considering this article for peer review in Journal of Dentistry and for the positive feedback.

In response to the reviewers' comments the reference number for ethical approval has been inserted in the main body of the text and underlined as per guidance notes.

Typos and grammatical errors have been addressed but not underlined in keeping with the guidance notes.

We look forward to receiving, what will hopefully be notification of acceptance for publication in Journal of Dentistry in the near future.

Kind regards,

(corresponding author)

Title page

Title: The experience among patients with multiple dental loss as a consequence of treatment for head and neck cancer: A qualitative study

Short title: Treatment-related dental loss among patients with head and neck cancer

Authors:
Ms Roisin S Parahoo, Dental student, QUB

Dr Cheirth J Semple, Reader in Clinical Care Nursing, Ulster University / SEHSCT, Belfast

Dr Simon Killough, Consultant in Restorative Dentistry, BHSCT

Prof Eilís McCaughan, Professor in Cancer Care, Ulster University, Coleraine, N Ireland

Corresponding author:
Dr Cherith J Semple, Reader in Clinical Cancer Nursing

Email address: cherith.semple@setrust.hscni.net

Postal address: South Eastern Health & Social Care Trust, Cancer Service, Ulster Hospital, Upper Newtownards Road, Belfast, N. Ireland, BT16 1RH.

Main body

1. Introduction

Head and neck cancer (HNC) incidence is steadily increasing worldwide, with 650,000 new cases and 350,000 deaths every year [1]. While in North America and Europe, HNC accounts for 5-10% of all new cancer cases, there is wide geographical variation in the incidence and anatomical distribution of HNC worldwide [2]. The risk of developing HNC is more common in males [1] and people of lower socio-economic groups [3,4,5].

Radiotherapy, surgery and chemotherapy are the main treatments of HNC. While they can be effective in treating this disease, they can have implications for the dental health status of patients diagnosed with this cancer. Dental loss is often a necessary part of a surgical resection for a tumour in the oral cavity. Radiotherapy to the HN area often leads to xerostomia (subjective complaint of a dry mouth), hyposalivation and impacts tooth structure by weakening dentine-enamel bonds which can increase the risk of dental decay [6]. In addition, if teeth are extracted after the mouth has been irradiated, osteoradionecrosis (ORN) may occur in the extraction site due to hypovascularity and reduced healing. As a consequence, teeth with a poor prognosis such as extensive dental caries, advanced periodontal disease or heavily restored are typically recommended for extraction prior to radiotherapy to prophylactically prevent this condition from occurring [7]. In general, patients who require multiple extractions pre-radiotherapy often are irregular attendees or not registered with a General Dental Practitioner, have dental anxiety and usually demonstrate poor engagement with dentistry. The extraction of teeth pre-radiotherapy is a controversial topic, as there is a lack of conclusive evidence that it reduces the development of ORN [8]. There is also a lack of research on the experience of dental loss among this population.

Scoping the literature, we found only one study on the impact of pre-radiotherapy on dental extraction on HNC [9]. This qualitative study was carried in one Health Trust in London. It reported that often teeth that were healthy, asymptomatic and not at the site of cancer were removed prior to radiotherapy (RT). This dental loss had a profound effect on their quality of life, post-treatment and less radical approaches to pre-radiotherapy dental planning should be considered [9]. The other studies in the literature focused on ‘onset and treatment of ORN’, ‘surgery and radiotherapy treatment’, ‘drugs used for the side effects of treatment’, ‘post-treatment complications’ and ‘dental care post treatment’. These studies mostly explored the issue of multiple dental extractions from health professionals’ perspectives. There is a lack of research focusing on HNC patients’ perceptions and needs prior to, and following, dental loss.

The impact of dental loss should be investigated from the patients’ perspective to understand their experience, views and needs in order to provide appropriate, person-centred, support and advice to help them at a vulnerable time, following a diagnosis of HNC. The aim of this study is to explore the experience of treatment-related dental loss among patients with HNC.

2. Methods

2.1 Recruitment of participants

A purposive sample of 15 patients who required multiple dental extractions as part of their treatment plan for HNC were interviewed. These participants were recruited from two Health and Social Care Trusts in Northern Ireland, who provide specialist HNC services to include surgery, radiotherapy and chemotherapy.

Purposive sampling was employed to ensure there was representation from a variety of factors including age, gender, socioeconomic backgrounds and treatment modality. Recruitment continued until data saturation was reached. Ethical approval was obtained from the NHS Research Ethics Committee (IRAS project ID: 240616). Participant inclusion criteria included patients aged 18 or over, aware of their cancer diagnosis, had multiple dental loss as part of their definitive treatment plan for HNC, who were on a curative treatment pathway and were at least two months post-treatment. Exclusion criteria involved patients who did not understand written or verbal English, and patients who suffer from dementia or had severe cognitive impairment.

2.2 Tool development

A topic guide for the interviews was developed based on the literature review and moderated by the steering group. The steering group involved a user, a researcher with a background in dentistry, a qualitative researcher, a HNC Clinical Nurse Specialist and a Consultant in Restorative Dentistry. The topic guide included topics such as the patient's journey from the time they were diagnosed, the information they received, the reasons for extraction, their feeling about losing their teeth, the effects of dental loss on their lives, their coping strategies with dental loss and their dental-related, rehabilitation journey. The semi-structured interview format allowed new themes to be brought to light by the participants themselves. There is no formal definition of multiple dental loss. For the purposes of this research, the team agreed an operational definition as the extraction or removal of two or more teeth as part of an individual's treatment plan for HNC.

2.3 Data Collection

The participants were interviewed in their own homes, using one-to-one semi-structured interviews. Interviews lasted approximately 30 to 60 minutes. They gave verbal consent when they attended clinics and were subsequently posted Participant Information Sheets. They were then contacted over the phone and a time was arranged to conduct the interview. Before the interview commenced, informed written consent was obtained. The participants were given the opportunity to ask questions and to withdraw at any time. The interviews were recorded and transcribed verbatim.

2.4 Data Analysis

The transcripts were analysed using thematic analysis as recommended by Miles and Huberman (1994), including the techniques of labelling, coding, categorising and themes development. Firstly, the codes were processed into themes with the use of spider diagrams and mind maps. Two researchers read the transcripts separately to generate themes, and a meeting of the research team was conducted to review and finalise the themes.

3. Results

3.1. Overview of the results

The research team discussed the interviews and the emerging themes throughout the data collection phase. Data saturation was reached within the time frame available for this study. Fifteen participants agreed and were interviewed (see Table 1). Ten were males and 13 of the participants were smokers. The profile of participants

seems to reflect the profile of HNC patients (males and smokers being more at risk of the disease). No data on socio-economic status were collected; however, the interviewer observed that most lived in lower socio-economic areas of Northern Ireland. Within this study, 14 had radiotherapy either on its own or with surgery and/or chemotherapy. The majority of participants were either Stage 3 or Stage 4a when diagnosed with HNC. The vast majority had squamous cell carcinoma, mostly in the oral cavity. Numerous participants had an immense degree of dental loss ranging from full clearance (n=7), almost full (n=1), lower (n=1), upper (n=1) with only two participants having two teeth removed. The full disease characteristics of the participants can be found in Table 2.

The interview data were categorised into four main themes: Pre-treatment experience of being informed that their teeth had to be removed, Impact of dental loss post-treatment, Coping with dental loss, and Getting dentures and implants. These four themes were generated by a number of sub-themes that are presented below. The numbers at the end of the quotes refer to individual patients.

3.2 Main theme 1: Pre-treatment experience of being informed that their teeth had to be removed

The three sub-themes that made up this main theme were: 'Reactions to dental loss - the similarities and differences between primary treatment modalities', 'Information and involvement in dental loss decision-making' and 'Priority: 'getting rid of the cancer''.

3.2.1 Sub-theme: Reactions to dental loss – the similarities and differences between primary treatment modalities'

There was a difference in reactions between patients who had primary surgery and patients who had primary radiotherapy (RT). Those scheduled for primary surgery, by in large, accepted the fact that some or all of their teeth were to be removed as the cancer affected part of their mouth which necessitated dental loss as part of the surgical tumour resection.

Just accept that the teeth have to come out because part of the jawbone had to come out. (P2)

The patients who had primary surgery were told about the need for teeth to be removed at an early conversation relating to their surgery. They were focused on 'the big surgery' and loss of teeth appeared to be less important. However, for patients receiving primary RT, getting teeth removed did not seem to be known until a short time before the extractions were scheduled.

Some participants accepted the recommendation that their teeth should be removed without questioning. They seemed to have faith in the dentists'/doctors' expertise, either because it was necessary as part of the tumour resection, or because their teeth were in 'bad condition'.

It was just a case of, if it has to be done, it has to be done. (P8)

Other participants, who perceived that their cancer did not affect their teeth were surprised when the recommendation was made to have some or all of their teeth removed. These were mainly patients about to receive primary radiotherapy.

> *I was not expecting it (tooth removal recommendation). It all happened so quickly it was a pre-requisite for the treatment, so it was the next day all the teeth out, that was it. (P10)*

This unexpected news was a surprise also because some *believed* their teeth were in good condition.

> *The teeth themselves were in pretty good nick. (P10)*

> *That was a bit of a shock as 10 teeth had to come out because at that stage I was thinking that my teeth weren't too bad but … the sheer number of teeth that had to come out… Immediately you are thinking from a vanity perspective how am I going to look, when am I going to get them in, am I ever going to get them in again, what do I do in the meantime. There is a lot of questions that go through your head when you hear that 10 teeth have to come out. (P15)*

3.2.2 Sub-theme: Information and involvement in dental loss decision-making

Patients undergoing surgical treatment stated that the surgery recommended included removal of teeth (e.g. getting a section of the jaw removed which included teeth). For other patients receiving primary radiotherapy, their understanding appeared muddled regarding the rationale for getting their teeth out. The information they recalled receiving was mainly about the detrimental effects of radiotherapy on teeth causing them to fall out and the difficulty of carrying out future dental work if they got an associated dental infection after treatment.

> *He said … my teeth would have to come out because when you are getting radiotherapy and stuff they would fall out anyway. Had to be done and that was it (P5)*

> *Infection, I think that is the big word that comes to mind, he seemed to indicate that if they didn't remove the teeth the radiotherapy would have a detrimental effect on your teeth and the structures around the teeth, which might in turn cause infection and this might involve further surgeries and what not, therefore to avoid at all cost getting an infection in the jaw area any teeth that had any cavities, dental work, should be removed (P15)*

Patients did not seem to be involved in the decision-making process regarding pre-radiotherapy dental extractions. When asked about options offered to them, they stated that there were none presented. However, to meet the objectives of this study we sought participants who had experienced multiple dental loss as a result of treatment for HNC. In reality, some patients do decline treatment for HNC or dental extractions. Due to the nature of this study, we were not able to explore those patients' perspectives.

> *They gave me radiation and they said I had to get all my teeth out because of the radiation. They'd fall out anyway; there was no option. I felt terrible. (P6)*
> *I was not presented with any alternatives. (P10)*

There seemed to be a belief among some participants that in order to have RT, they have to have their teeth removed. Participants felt it was a choice between dental loss and RT and there was not another option.

Some participants also reported that the time between being told their teeth had to come out and receiving radiotherapy was very short which 'did not give much time to come to terms' with it. This varied between one day and a week.

I was told about this two days before the teeth were removed. I was given little preparation. (P6)

One man, who received RT, who was told that he had to have four molars out, did question this decision. The same day he was sent for another assessment and he was told he needed a dental clearance. He then visited his own dentist and told them about the forthcoming extractions:

> *On the Friday, at my own dentist's, I had three dentists arguing between themselves, was this the right decision [for a dental clearance] or was this the wrong decision? And me as a lay person, I didn't know. I had no time to put this all through my computer and make my own mind up. I was just told no, you're getting them all out and that's it. (P13)*

The same participant said that he needed more time to digest what he was being told. Another man, on hindsight, explained what more time to think about losing teeth would mean to him.

> *I would have appreciated not having this thing about the teeth extraction thrown to me as an add on at the very last minute. If I had been given more time, I would have probably said, well let's take the chance, leave the teeth in situ and if necessary extract them at a later stage. (P10)*

3.2.3 Sub-theme: Priority: 'getting rid of the cancer'

There was a feeling among most participants (at the early stages) that cancer was their main worry rather than considerations surrounding the loss of their teeth. The thought of having cancer and the impending treatment was foremost in their mind.

I was facing a cancer operation. I wasn't worried about teeth, you know? (P1)

However, for some the thought of getting their teeth out did cause some concern, primarily thinking about how they would look without teeth. As one participant said, his "face would collapse" and he would "look like an old man" before his time.

3.3 Main theme 2: Impact of dental loss post-treatment

The two sub-themes are: 'Eating and speaking' and 'Facing unexpected challenges'. Participants reported that dental loss affected them in a number of ways. It is not possible to separate the effects of the cancer and its treatment from those of dental loss on the lives of the participants, especially immediately after treatment when the adverse effects were most apparent. However, from their responses, dental loss seemed to add significantly to the detrimental effects of cancer treatment to include both surgery and/or radiotherapy.

3.3.1 Sub-theme: Eating and speaking

There was a sense of daily struggles with food. Although, for some, there was a loss of taste as a result of treatment, most participants also experienced difficulties with chewing, biting and swallowing. Even those

patients that had been fitted with dentures struggled with eating and chewing. The challenges they face trying to feed themselves are depicted in the following quote:

> *You have to cut it up so small and then still to be able to chew it, you are trying to get it on your gum so you can chew… And then you get it down and you swallow it and you've had about ten mouthfuls and it's cold. And your jaws are sore. (P2)*

Some participants spoke about food they craved for but could not eat, in particular, steak.

Many participants were conscious of the impact less or no teeth had on their ability to speak clearly which they found embarrassing and for some it reduced their social interactions.

> *It's embarrassing to talk with no teeth on. I look stupid. (P6)*

Talking on the phone seemed to be particularly challenging with participants being told by the caller that they could not understand them. This resulted in reluctance to use the phone. One participant who said she had "good and bad days where the speaking is concerned" explained that "fifteen minutes after putting on her dentures" she gets adjusted to it and can speak better. But she explained:

> *Maybe this is a mental thing, but if I am on the phone and I have my teeth in, I'll try and whip them out because I think they can understand me better with my teeth out. (P8)*

3.3.2. Sub-theme: Unexpected challenges

The changes in eating habits did impact on people's bodies. For example, some patients complained about experiencing severe constipation due to the liquidised food they were now consuming. They had not been prepared for this symptom and had found it difficult to attain regular bowel motions.

> *I was living entirely on these protein drinks…no solid food at all, the effect of that of course were things like faecal impaction and all sorts of problems that weren't pleasant. (P10)*

All patients had experienced a significant weight loss and were actively trying to put weight on through their altered and limited diet. Some patients recognised that this weight loss 'had been a good thing' but most were concerned and stated that it made them look different from before.

Intimacy with partners also affected several patients, stating how 'things had changed' since getting the teeth out. Some patients spoke about how it was 'not the same' and appeared sad that it was 'different now'.

> *Now we hug and hug and peck and everything but just actually kissing, the thought of X (husband's) tongue even going in … it's just taking something away from me. (P2)*
>
> *When you're trying to be intimate you are very aware that you have a hole in your mouth. You feel like half a kiss, would you like to kiss someone with no teeth sometimes is the question you are asking yourself, is that off putting? (P15)*

3.4 Main theme 3: Coping with dental loss

The Sub-themes are: 1. Trial and error, 2. Social withdrawal, and 3. Getting on with life. Over time, participants and their families developed ways to cope with their eating difficulties. One participant explained that it was 'a learning curve and that everybody is different'.

3.4.1. Sub-theme: Trial and error

Most patients learnt by 'trial and error' what they could eat and how they could eat. Solid food was 'blitzed', pureed', 'liquidized' or 'mashed'. Eating habits had to change and favourite foods replaced. It was a slow and difficult learning process.

> *If today, you have something you say … I'll try something a wee bit bigger tomorrow. Whereas if you just did what they [the dieticians] told you, you'd be eating the same thing for weeks and then you would be sick and you wouldn't want to eat it. (P2)*

Most patients were actively increasing their calorie intake to put on weight and this resulted in consuming large amounts of unhealthy food. They had been advised by the dietician to 'add cream to everything'. One participant explained how she coped with her eating and weight difficulties by eating food such as 'fresh cream swiss rolls or sponge or something and custard'. She acknowledged that…

> *It hasn't got the goodness of food, but it's filling me up. It's bad for everybody but it's good for me. (P2)*

Patients seemed to take the lead in their own eating recovery through this trial and error strategy. Formal dietary advice was not always followed. Some felt that dieticians concentrated too much on 'nutrition' and 'weight' and did not understand the relationship between people and food.

> *I'm afraid it was led by me, I don't pay a lot of attention to what dieticians say. But whatever you can eat, a little of what you fancy is the answer. It's no good giving yourself a strict diet of X, Y and Z, and living off nothing else. Because A you will go mad and B, I'm sorry it would kill you. (P4)*
> *I don't think anybody understands until they have gone through it themselves. But I don't think she [dietician] understood the relationship with food. (P7)*

3.4.2 Sub-theme: Social withdrawal

Several participants said they did not go out to eat as they could not consume the food on offer. This reduced their social activities significantly. Some would phone and see if the restaurant was able to provide food that they (participants) could eat. One participant explained that she would "always try and get a wee corner" in a restaurant because she did not want to be noticed. Another would invite friends to her place rather than going out to eat as she would have control over the menu.

> *It impacts on you socially; I don't go out to restaurants anymore which I used to do quite a lot. I don't mind eating in front of my immediate family because they're obviously aware of the situation. But I am very reticent about eating in front of strangers (P10)*

Most participants dreaded occasions such as weddings or other celebrations which involved communal eating. This greatly impacted on their social life.

> "*a nephew got married recently, and I couldn't go to the wedding." [P11]*

Others expressed concern over how loosing their teeth had changed their appearance, to include looking older. Dental loss appeared to have a negative cosmetic impact with some participants sharing about 'loss of confidence' to go out and being 'self-conscious' that people would be staring at them.

I don't know if it's self-consciousness on my behalf now, but it feels as if people were staring at you. Well, why me, why did they have to take out all your teeth? And then you have to go into the whole, wring it all out and explain it. (P13)

3.4.3 Sub-theme: Getting on with life

Despite 'ups and downs' of post-treatment challenges, there was a strong sense of hope and perseverance as well as acceptance of their situations, among many of the participants.

I wouldn't say it gets better, it gets easier because you become accustomed to the new norm as it were, so this is as good as it is gonna get. It's a case of get on with the hand you've been dealt. (P10)

With some patients demonstrating a strong sense of resilience and acceptance.

You don't have a choice, you have to really get your head round it. It doesn't bother me that I have no teeth here, it doesn't bother me that I am scarred on the side of my face or on my leg. I wear shorts, I wear dresses. If it annoys someone else, I'm sorry. And I'm just determined that I have things in my life that I still want to do. (P7)

However, there was also a realisation that things were different now and that in some cases participants felt unprepared and saddened.

I mean the change from having teeth to no teeth is so vast. I mean it took me by surprise. Nobody explained the contrast beforehand. And that's where I was lost. (P13)

Participants who received primary radiotherapy explained what they would have done different if they could go back and offered some advice to others who may be at the start of this journey:

Regret, Well? I did say to my own dentist when he was fitting these, I said I'm really pissed off about this because I did have a lovely set of teeth. He goes, yes you did, the other problem is they are in the bin now instead of your mouth. (P10)

I'd say, hang on to your teeth. At all costs, hang on to your teeth. (P13)

However, the patients who had dental loss due to surgical resection did not seem to regret going through with the operation. It seemed the challenges that the surgery caused, including removal of teeth, were more acceptable as it would have been impossible to remove the cancer otherwise.

3.5 Main theme 4: Getting dentures and implants

Sub themes: 1. The teeth replacement journey and 2. Teeth replacement; living with the reality.

In the pre-treatment stage, patients had believed that soon after treatment, their teeth would be replaced by 'false teeth', either dentures or implants. However, in reality, the process and outcome of this quest, proved to be a complicated and unsatisfactory journey.

3.5.1 Sub theme: The teeth replacement journey

The length of time from treatment to getting teeth replaced varied significantly between patients, with one patient who was three years following radiotherapy and had not been fitted with his first set of dentures. Patients seemed unaware of the procedure and pathway for dental rehabilitation, with some initiating appointments with their own dentist, while others attended the dental hospital.

One patient, who was treated in two hospitals for their cancer treatment, felt that the surgical and radiotherapy teams met weekly and worked together as a team, but that "the dentistry part of it…. There wasn't that closeness between them, they didn't seem to talk" (P1).

Patients sourced their dentures from their own dentists or from the dental service in a hospital. Some patients were unsure as to what would be available from the National Health Service, whereas others could not wait and decided to pay for it. There was some confusion as to whether they were entitled to free implants. Patients reported having had implants while others felt that their requests for implants were turned down and did not fully understand why. One patient who wanted implants was told he could have 'permanent dentures'. He was unsure what these were:

> *I'm like right, dead on. So, for a lot of weeks, I was mulling it over in my head, what's permanent dentures? Asking friends that were coming over and what not. They're going, must be implants. (P13)*

At a subsequent visit to the hospital he was told that they were dentures not implants; he was disappointed. Although comments were made about the slow service and the uncertainty of what they are entitled to, as well as when they could expect to get dentures, most participants found the hospital dentists and their own dentists to be very helpful and accommodating.

For others, moving onto dental rehabilitation was viewed positively, offering a sense that the end goal was in sight or the final part of this challenging treatment journey was being reached.

> *The dental work seemed to put to the end… but when you get the dental work, the process initiated, you feel you are getting to the end, you're getting through and the dental work at the end starts to pick you up. (P15)*

3.5.2: Sub-theme: Teeth replacement; living with the reality

For most patients, the reality of dentures replacing their original teeth was disappointing. Patients had on-going challenges with dentures (poorly fitting, discomfort to the gums, poorly retained to include falling out when eating) and had had them replaced two or three times. Trying to get new ones took longer than expected and due to clinical reasons longer than desired, which caused a lot of frustration. For some patients they eventually gave up in their quest for replacement teeth.

> *We tried to get dentures in an ordinary dental practice but they couldn't get the bottom ones to fit properly. (P11)*
>
> *I feel down, feel sometimes that you want to punch a wall, like, you know? If I could get these dentures [second pair] tomorrow, I would go for it. But they're adamant, no, it's September like. (P13)*

Patients' expectations of dentures appeared different than what their experience was. They seemed to struggle to *'function'* with the teeth, repeatedly expressing disappointment. However, patients did seem hopeful that they would eventually get '*teeth*' that would fit and were prepared to attend frequent appointments to attain this.

For those few who managed to get dental rehabilitation that optimally restored both function and appearance this had a significant positive impact on their recovery, especially their emotional wellbeing.

> *Dental work does matter from a mental point of view and how you have this vision of yourself. Teeth does give you confidence, it makes you feel more secure...Now that the dental work is done it is class. A number of things has happened, even purely from a physical appearance and from a vanity perspective*

being able to smile again and talk properly it has such a feeling of wellbeing comes over you again, it's amazing how your association of teeth and how you are as a person, especially your four front teeth. (P15)

4. Discussion

This study has raised a number of issues regarding information related to pre-radiotherapy dental extractions. The key areas that unfolded were participants' very short notice about getting teeth removed, limited understanding surrounding rationale for dental extractions and their lack of choice and involvement in decision-making. The findings have also provided an insight into the significant impact of dental loss on patients' lives, how they coped on a daily basis and their long and difficult quest for dental rehabilitation such as dentures and implant retained dentures, in the aftermath of treatment.

Patients who were having surgery, understood that dental loss was a perquisite to enable resection of the tumour, in pursuit of surgical clearance of the cancer. The patients' perception of the rationale for pre-RT tooth removal can be summed up as follows: RT may lead to infection (in particular ORN), their teeth may fall out or lead to more dental related problems in the future which would prove very difficult to manage. These reasons seemed to be concerned primarily with preventing potential complications, with less consideration given to impact of dental loss on quality of life and how best to maintain and preserve post-radiation dental functionality. This pre-radiation approach in performing dental extractions for teeth with questionable prognoses [10] is recommended practice by the RDUK (2016). However, the extraction of teeth pre-radiotherapy is a controversial topic as there is inconsistent evidence regarding the development of ORN [11]. Some studies showed the benefits of extraction, some showed no difference between extraction and no extraction while others reported an increase in the risk of developing ORN, following extraction [11]. A Cochrane review found no randomised controlled trials comparing extraction of teeth prior to radiotherapy with leaving teeth in situ during radiotherapy to the jaws [8].

In this study, the majority of patients were male, smokers from lower socio-economic backgrounds with an advanced stage of HNC, requiring multiple modality treatment and had a heavy burden of dental loss related to their HNC treatment. Although, not an uncommon demographic profile for HNC, it is important to note that this is a subset of the population living with HNC, but this subset often have poor dental health and lack of engagement with their dentists. Furthermore, this study was solely qualitative in nature, purposing to extrapolate patients experience and views surrounding treatment –related multiple dental loss and therefore findings haven't been triangulated with clinical data generated from dental assessment or their dental radiographs. However, teeth that are typically recommended for extraction pre-RT are those with a poor prognosis with extensive dental caries, advanced periodontal disease or if they have been heavily restored. The RDUK (2016) fully acknowledges that recommendations for dental extractions are often based on expert opinion, in the absence of a robust evidence base.

Those who were embarking on a course of RT (and required pre-RT dental extractions), seemed to perceive that they had the option of keeping their teeth or having RT, not that they can keep their teeth and have RT. In this study, only one patient pre-RT raised the possibility of keeping his teeth with dentists, but he reported being told that all his teeth should be removed. None of the patients reported that the information they received included reference to the lack of conclusive research evidence to support the practice of pre-RT tooth removal to prevent ORN. It's important to acknowledge that HNC patients are meeting the dental team at a stressful juncture in their cancer pathway, when they

are often in a state of shock or denial, many experiencing distress and having difficulty with processing information. Nonetheless, there is number of essential stages in shared decision-making have been identified [12][13], including the presentation of options to patients, which involves making the patient "aware of a position of equipoise or balance, where there is no right or wrong decision, only a preferred choice" [12]. This seems to apply perfectly to the issue of pre-RT tooth extraction as there is no conclusive research evidence to support this practice, with the exception of those teeth with a hopeless prognosis. Therefore, more discussion could be anticipated if patients were made aware of this fact.

There was no indication that any of these patients, about to receive primary RT, were involved in shared decision-making regarding the need for tooth removal. Shared decision-making, which is advocated by the United Kingdom government, "involves the provision of evidence-based information about options, outcomes and uncertainties, together with decision support counselling and a system for recording and implementing patient's informed preferences" [14]. In this study, patients who perceived that tooth removal was part of their surgical resection and those who perceived their teeth as being in poor condition, agreed with the surgeons' and dentists' recommendation. It is possible that the patients who are receiving radiotherapy but perceived their teeth to be healthy and had not fully understood the rationale for dental extraction, would also understand the need for tooth removal in these circumstances.

Patient education and shared decision-making needs to be an integral part of the pre-treatment dental assessment and should include a discussion of potential oral complication, the inconclusive evidence surrounding pre-radiation dental extraction in preventing ORN, how the patients can minimise oral complications with optimal oral hygiene and avoiding tobacco. Both evidence based practice and person-centred care are made up of three main components: 'clinician's expertise', 'patients' wishes and preferences' and 'research evidence' [15]. In this study, it seems that the key component used in making decisions was clinician's expertise. We would advocate placing greater emphasis on pre-treatment shared decision-making surrounding tooth removal. With adopting such an approach, it is hoped that as people live with and beyond their cancer, they would view dental loss as clinically justified, perceiving it as a need rather than getting frustrated and regretful later on.

Another issue that patients in this study highlighted was being told, at very short notice, that their teeth had to be removed, prior to RT. There was also little time between being told this surprising news and the actual extractions, especially at time where they were particularly vulnerable, following a cancer diagnosis. The accepted interval, for clinical reasons, between extractions and radiotherapy is 10 days to three weeks [10]. Practical reasons for this 'speed' of treatment may include the pressure to meet cancer targets but also to make sure patients are treated as quickly as possible to improve survival outcomes. On the other hand, patients have little time to digest such news, look for information, talk to others or even to seek a second opinion. Therefore, patients who are going to lose their teeth due to their HNC should be forewarned in plenty of time so they are expecting it. The patients who are having teeth removed prior to radiotherapy should have earlier provision of information so as dental loss is not perceived as an 'add on' or unexpected.

This issue of time was also reported in a recent qualitative study of the impact of pre-radiotherapy dental extractions in HNC in an NHS Trust in London [9]. The authors of this study argued for patients to be given the option of delaying decision-making in relation to dental extractions of teeth that are healthy and asymptomatic until after the

completion of RT, particularly where extractions are not part of surgery [9]. This would be in line with another principle of shared decision-making regarding deferring decisions until "patients have considered the options without time pressure and consulted decision aids or significant others", especially in cases where there is a lack of 'clear cut' options [17].

Patients find it difficult to hear, comprehend and digest all the information given to them at the time they are told they have cancer [18]. A cancer diagnosis triggers a rollercoaster of emotions and feelings, including anxiety, fear, hope, helplessness, courage and despair [18][19]. It is, therefore understandable that their main worry is cancer not teeth. This why a delay regarding dental extraction until after cancer treatment makes more sense in cases where 'healthy' teeth are concerned. This was also a suggestion made by two participants in this study. Currently there is no universally accepted pre-cancer dental protocol because of the lack of clinical trials evaluating the efficacy of pre-treatment dental extractions. Further research is also required to identify treatment related factors on dentition such as dose of radiotherapy, impact of concurrent chemotherapy, location of teeth within the radiotherapy field and use such evidence to develop national protocols to aid a more comprehensive discussion with patients. This is especially pertinent in the current modern era were delivery of RT by intensity-modulated radiation therapy (IMRT) is now considered the standard of care, which significantly reduces the incidence of xerostomia and recovery of saliva secretions [20].

This study has also provided a window into the devastation that dental loss has brought to their lives, irrespective of whether patients had surgery or radiotherapy alone or multi-modality treatment. The psychosocial effects of HNC, such as altered body image, disfigurement, intimacy issues, and eating, swallowing and speaking difficulties, have been well documented in the literature [21][22][23]. It was difficult, in this study, to separate the effects of cancer and treatment from the impact of dental loss. However, it was clear that dental loss added to the distress of these patients after treatment for all patients in this study irrespective of rationale leading to dental loss. This is supported by the findings of the London study that not having teeth was felt more than the effects of cancer [9]. In both this study and the London one [9], some participants used a language and tone that conveyed anger, frustration as well as regret at having lost 'good' teeth. It slowly dawned on these patients, in the current study, that having their own teeth meant a lot to them and that their lives were seriously diminished without them. Dentures, which some thought was a potential good replacement for teeth, were difficult to manage and caused problems of their own in terms of eating, speaking and appearance.

In nearly all their responses, the narratives were about dental loss affecting how and what they ate and the enjoyment out of eating. Some told about their love for food and cooking and the food they now craved, especially 'steak and chips'. Feeding themselves had become a daily chore for them and their partners. Going out to eat, which they enjoyed, was not an option for some of them. An important part of their social life was hindered by dental loss. Socially these patients were missing out on a vital part of routine and pleasurable living. Research has shown that 'shared meals, routine conversations, and family rituals promotes a sense of closeness, connectedness and stability" [24]. Data from a United Kingdom national survey showed that "those who eat socially more often feel happier and are more satisfied with life, are more trusting of others, are more engaged with their local communities, and have more friends they can depend on for support" [25]. Health professionals should be aware that, apart from not being able to eat, people's social enjoyment and their social network and activities can be significantly curtailed as a result of dental loss.

Many participants in this study talked about their resilience in coping with their difficulties. However, their adaptation to a 'new normal' was a slow, painful and frustrating process of trial and error. Their several attempts to find dentures that fit show that there were no clear rehabilitation pathways for these patients. They would benefit from knowing what they can expect, when and where. It is recommended that the final oral rehabilitation should be considered at the beginning of treatment [8].

4.1 Rigour

Qualitative researchers use different criteria to reflect the quantitative research concepts of validity and reliability. They use the concept of trustworthiness which has four dimensions: truth-value, applicability, consistency and neutrality [26]. Truth value was achieved by the interviewer summarising the participant's responses, at the end of the interview, to ensure that the interviewer's understanding and interpretation were not different from that of the participant.

An audit trail [27], in relation to all methodological decisions, is presented in this paper. The research team met throughout the data collection to ensure that relevant questions were explored in the interviews. Data analysis was separately carried by two researchers (one with a background in dentistry and the other one with significant experience in qualitative research). The research team also discussed the findings to ensure consistency and neutrality.

We also ensured that the sample was representative of the population in relation to age, gender, social class background, recently diagnosed and those with a longer time from diagnosis (to reflect their experience over a longer timeframe) and different treatment modalities.

4.2 Limitations

One of the limitations of this study is the difficulty participants may have had in recalling past events and how they felt at the time. The length of time between treatment and the research interview varied between a few months to eight years. The pre-treatment period (post-diagnosis) would also have been a time when they were probably experiencing emotional turmoil and could only selectively remember what happened. However, there is no way of knowing if this happened. From the point of view of the interviewer, the responses of those who had their treatment a long time ago seemed to be as vivid as those who were treated recently.

Some of their accounts could have been viewed though the lenses of how they were feeling at the time of the interview. If they were having problems with dentures and were feeling frustrated, it is likely that they would have been more critical or negative regarding the advice and treatment they received. However, there is no way of knowing if this happened.

In this study, participants could only tell us their 'perception' of what happened not necessarily what happened. The health professionals they interacted with would probably have different perceptions of the same situations. However, it is important to know patients' perceptions even if they do not correspond to those of health professionals, as well as the reasons why they differ, if this is the case. Interviewing patients and health professional in the same study would be quite informative. An observational study of the interaction between patients and dentists, when they are discussing the need for tooth removal, would also provide useful data.

5. Conclusions and clinical implications

The main clinical implication of this study's findings is centred on information giving and shared decision-making. Information regarding the possibility of treatment-related dental loss should be presented earlier in the treatment pathway and therefore not considered by patients as an 'add on at the last minute'. Patient-clinician consultations should also include the impact of dental loss on daily living and the lack of robust evidence of pre-RT dental extractions to prevent ORN. This would aid shared decision-making, within a patient-centred care framework, being implemented in everyday practice. The principles underpinning shared decision-making are clearly laid out [16]. Patients need to be offered an informed choice especially when there is a poor evidence base, being mindful however, that every patient is different and has different perceptions and roles in decision making. A recent systematic review of the dental literature showed that the concept of patient-centred care is "neither clearly understood nor empirically and systematically assessed in dental settings"[28]. Through education, research and policy there needs to be a greater awareness to achieve the goals of shared decision with this population.

There is also a need to have clear pathways regarding post-treatment rehabilitation, especially in relation to dentures and implants. This should start much earlier in the patient cancer journey, preferably as part of the pre-RT tooth extraction decision-making process.

Using a qualitative approach, this study provided a window into peoples' thoughts, perceptions, behaviour and needs. It has provided a greater awareness of the post-treatment implications of dental loss on patients' everyday lives, which is clearly aligned to the National Cancer Research Institutes (NCRI 2018) top research priorities for living with and beyond cancer [29]. It has shown that qualitative research can add to the armoury of research designs in dentistry to help dentists and others to understand what matters most to patients and the positive and negative effects that their care and treatment have on them.

REFERENCES

[1] A. Argiris, M. V Karamouzis, D. Raben, and R. L. Ferris, “Head and neck cancer.,” *Lancet (London, England)*, vol. 371, no. 9625, pp. 1695–709, 2008.

[2] Vigneswaran N & Williams MD. (2014) Epidemiological trends in head and neck cancer and aids in diagnosis.

[3] S. A. Duffy, J. E. Terrell, M. Valenstein, D. L. Ronis, L. A. Copeland, and M. Connors, “Effect of smoking, alcohol, and depression on the quality of life of head and neck cancer patients,” *Gen. Hosp. Psychiatry*, vol. 24, no. 3, pp. 140–147, 2002.

[4] E. M. Sturgis and P. M. Cinciripini, “Trends in head and neck cancer incidence in relation to smoking prevalence: An emerging epidemic of human papillomavirus-associated cancers?,” *Cancer*, vol. 110, no. 7. pp. 1429–1435, 2007.

[5] I. Al-Dakkak, “Socioeconomic status and head and neck cancer.,” *Evid. Based. Dent.*, vol. 11, no. 2, pp. 57–8, 2010.

[6] K. Bjordal, S. Kaasa, and A. Mastekaasa, “Quality of life in patients treated for head and neck cancer: a follow-up study 7,” *Int J Radiat Oncol Biol Phys*, vol. 28, no. 4, pp. 847–856, 1994.

[7] P. J. Hancock, J. B. Epstein, and G. R. Sadler, “Oral and dental management related to radiation therapy for head and neck cancer. [Review] [33 refs],” *J. Can. Dent. Assoc.*, vol. 69, no. 9, pp. 585–590, 2003.

[8] S. Eliyas, A. Al-Khayatt, R Porter, P Briggs. Dental extractions before radiotherapy to the jaws for reducing post-radiotherapy dental complications. *Cochrane Database Syst Rev* 2013; CD008857. Available online at http://cochranelibrary-wiley.com/doi/10.1002/14651858. CD008857.pub2/pdf (accessed 5 Oct 2018).

[9] S. Clough, M. Burke, B. Daly, and S. Scambler, “The impact of pre-radiotherapy dental extractions on head and neck cancer patients: A qualitative study,” *Br. Dent. J.*, vol. 225, no. 1, pp. 28–32, 2018.

[10] RD-UK, "Predicting and Managing Oral and Dental Complications of Surgical and Non-Surgical Treatment for Head and Neck Cancer: A Clinical Guideline". https://www.restdent.org.uk/uploads/RD-UK%20H%20and%20N%20guideline.pdf., 2016, (accessed 27th August 2018).

[11] N. Beech, S. Robinson, S. Porceddu, and M. Batstone, “Dental management of patients irradiated for head and neck cancer,” *Aust. Dent. J.*, vol. 59, no. 1, pp. 20–28, 2014.

[12] G. Makoul and M. L. Clayman, “An integrative model of shared decision making in medical encounters,” in *Patient Education and Counseling*, 2006, vol. 60, no. 3, pp. 301–312.

[13] F. Ryan and S. Cunningham, “Shared decision making in healthcare,” *Fac. Dent. J.*, vol. 5, no. 3, pp. 124–127, 2014.

[14] NHS England, “Shared decision making,” *Shared decision making*, 2017. [Online]. Available: https://www.england.nhs.uk/rightcare/shared-decision-making/#%0Ahttps://www.england.nhs.uk/ourwork/pe/sdm/, (accessed 26th August 2018).

[15] R. B. Haynes, P. J. Devereaux, and G. H. Guyatt, “Clinical expertise in the era of evidence-based medicine and patient choice,” *Evid. Based. Med.*, vol. 7, no. 2, pp. 36–38, 2002.

[16] A. Coulter, A Collins, "Making shared decision a reality: No decision about me, without me," London. Kings Fund Publications, 2011

[17] A. M. Stiggelbout *et al.*, “Shared decision making: Really putting patients at the centre of healthcare,” *BMJ (Online)*, vol. 344, no. 7842. 2012.

[18] E. McCaughan and H. McKenna, “Never-ending making sense: Towards a substantive theory of the information-seeking behaviour of newly diagnosed cancer patients,” *J. Clin. Nurs.*, vol. 16, no. 11, pp. 2096–2104, 2007.

[19] S. Blödt *et al.*, “Understanding the role of health information in patients’ experiences: Secondary analysis of qualitative narrative interviews with people diagnosed with cancer in Germany,” *BMJ Open*, vol. 8, no. 3, 2018.

[20] C.M. Nutting, J.P. Morden, K.J. Harrington et al. 'Parotid-sparing intesity modulated versus conventional radiotherapy in head and neck cancer (PARSPORT): a phase 3 multicentre randomised contolled trail. Lancet Oncology, vol 12, 127 - 136, 2011.

[21] M. B. Howren, A. J. Christensen, L. H. ynd. Karnell, and G. F. Funk, “Psychological factors associated with head and neck cancer treatment and survivorship: evidence and opportunities for behavioral medicine,” *Journal of consulting and clinical psychology*, vol. 81, no. 2. pp. 299–317, 2013.

[22] C. Semple, K. Parahoo, A. Norman, E. McCaughan, G. Humphris, and M. Mills, “Psychosocial interventions for patients with head and neck cancer.,” *Cochrane database Syst. Rev.*, no. 7, p. CD009441, 2013.

[23] S. Taylor, “The psychological and psychosocial effects of head and neck cancer,” *Cancer Nurs. Pract.*, vol. 15, no. 9, pp. 33–37, 2016.

[24] S. Whitbourne, "The Simplest Way for a Couple to Boost Intimacy," *Psychology Today*, https://www.psychologytoday.com/gb/blog/fulfillment-any-age/201509/the-simplest-way-couple-boost-intimacy , 2015 (accessed 26th August 2018).

[25] R. I. M. Dunbar, “Breaking Bread: the Functions of Social Eating,” *Adapt. Hum. Behav. Physiol.*, vol. 3, no. 3, pp. 198–211, 2017.

[26] Y. S. Lincoln, E G Guba, *Naturalistic Inquiry*, first ed., Newbury Park, CA: Sage Publications, 1985.

[27] Z. R. Wolf, “Exploring the audit trail for qualitative investigations.,” *Nurse educator*, vol. 28, no. 4. pp. 175–178, 2003.

[28] S. Scambler, M. Delgado, and K. Asimakopoulou, “Defining patient-centred care in dentistry? A systematic review of the dental literature,” *British Dental Journal*, vol. 221, no. 8. pp. 477–484, 2016.

[29] NCRI (2018) UK Top 10 living with and beyond cancer research priorities. https://www.ncri.org.uk/wp-content/uploads/2018/11/UK-Top-living-with-and-beyond-cancer-research-priorities.pdf accessed 22 Nov 2018.

Table

Table 1 & 2

Participant	**Gender**	**Age**	**Treatment Modality**	**Diagnosis date**	**Smoker**
P1	M	59	Surgery + XRT	Aug ‘17	Y
P2	F	59	Surgery + XRT	May ‘17	Y
P3	M	60	Surgery + chemo + XRT	Sept ‘17	Y
P4	M	80	Surgery	Feb ‘10	N
P5	M	61	Surgery + XRT	Jan ‘15	Y
P6	F	61	Chemo + XRT	May ‘12	Y
P7	F	60	Surgery + chemo + XRT	Oct ‘16	Y
P8	F	56	Surgery + XRT	1)‘13 2)’16 3)‘18	Y
P9	M	65	Chemo + XRT	May ‘16	Y
P10	M	62	XRT	Jan ‘16	Y
P11	M	62	Chemo + XRT	Nov ‘15	Y
P12	F	78	Surgery + XRT	Aug ‘15	N
P13	M	52	XRT	May ‘18	Y
P14	M	51	Surgery + XRT	Nov ‘15	Y
P15	M	59	Surgery + XRT	Aug ‘17	Y

Table1: Characteristics of participants

Disease Characteristic		**Number of Participants**
Staging	Stage 1	0
	Stage 2	2
	Stage 3	6
	Stage 4a	7
Histology	Squamous cell carcinoma	14
	Chondrosarcoma	1
Site of primary tumour	Oral Cavity	11
	Oropharynx	3
	Larynx	1
Teeth removed	Full dental clearance	7
	20 teeth from upper and lower	1
	10 teeth from upper and lower	1
	Lower dental clearance	1
	Upper dental clearance	1
	6 teeth from lower arch	2
	2 upper teeth	2

(Table 2: Disease Characteristics)

*Permission Note

Dear Mr Christopher D. Lynch,

TITLE of manuscript - The experience among patients with multiple dental loss as a consequence of treatment for head and neck cancer: A qualitative study

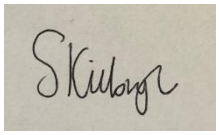
As Editor-in-Chief, all four authors below would kindly request that the above manuscript would be considered for publication in Journal of Dentistry.

We all affirm that the paper has been submitted solely to Journal of Dentistry and that it is not concurrently under consideration for publication in another journal. Furthermore, we wish to confirm that the submitted work, including tables, are original.

Kind regards,

Ms Roisin S Parahoo, Dental student (MSc Global Health), QUB

Dr Cheirth J Semple, Reader in Clinical Care Nursing, Ulster University / SEHSCT, Belfast



Dr Simon Killough, Consultant in Restorative Dentistry, BHSCT

Prof Eilís McCaughan, Professor in Cancer Care, Ulster University, Coleraine, N Ireland

***Conflict of Interest Statement**

Declaration of interests

☒ The authors declare that they have no known competing financial interests or personal relationships that could have appeared to influence the work reported in this paper.

☐The authors declare the following financial interests/personal relationships which may be considered as potential competing interests: